



Myalgic Encephalomyelitis/Chronic Fatigue Syndrome



MAY 10, 2024

CDC's website is being modified to comply with President Trump's Executive Orders.

Manage Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

KEY POINTS

- There is no cure or approved treatment for myalgic encephalomyelitis/chronic fatigue syndrome.
- However, some symptoms can be treated or managed.
- Taking these actions may provide some relief for people's worst symptoms and improve quality of life.
- Unfortunately, these strategies may not be effective for everyone who has ME/CFS.



Overview: treatment and management

ME/CFS is a particularly difficult disease to treat or manage because its cause remains unknown. Treatment is also complicated by the fact that the disease affects people differently. So, there is no one-size-fits-all solution to managing the disease.

People with ME/CFS, their families, and healthcare providers need to work together to decide which symptom causes the most problems. This should be treated first.

Before starting a management plan, people with ME/CFS, their families, and healthcare providers should also discuss the treatment. This discussion should include the possible benefits and harms of any treatment plans, including medicines and other therapies.

Healthcare providers need to support their patients' families as they come to understand how to live with this life-altering illness. Providers and families should also remember that this process might be extremely difficult for people with ME/CFS.

Symptoms to potentially address

Post-exertion malaise

PEM symptoms can be severe. They can begin shortly after the exertion or several days later. Typically, symptoms get worse 12 to 48 hours after the activity or exposure. Symptoms can last for days or even weeks.

PEM can be addressed by **activity management**, also called **pacing**. The goal of pacing is to learn to balance activity and rest to avoid PEM flare-ups.

To do this, people with ME/CFS need to **find their individual limits** for mental and physical activity. Then, they need to plan activity and rest to stay within those limits. Some patients and doctors refer to staying within these limits as staying within the "**energy envelope**."

People with ME/CFS have different limits for physical or mental activity, compared to others without the disease. Keeping activity and symptom diaries may help them find their personal limits, especially early in their illness.

Being mindful of personal limits can help people with ME/CFS cope with their illness. It can help them feel like they are managing the illness, rather than the illness controlling them.

People living with ME/CFS may find that everyday activities may be enough to cause a relapse or "crash". Activities such as buying groceries, brushing their teeth, or interacting with others may bring on PEM. It's hard to avoid these situations. But people with ME/CFS can learn to monitor their activities throughout the day. Then, they can place limits on what they do if needed.

When having a good day, people with ME/CFS may be tempted to try and "push." This involves increasing activity beyond what the person would normally attempt, often to make up for lost time. However, this can then lead to a "crash", or worsening of ME/CFS symptoms. The cycle can then repeat itself after people start recovering from the crash.

Rehabilitation specialists or exercise physiologists who understand ME/CFS may help people with ME/CFS adjust to living with the disease. Finding ways to make activities easier may be helpful. Some examples may include sitting while doing the laundry or showering, taking frequent breaks, and dividing large tasks into smaller steps.

Some patients find wearing heart rate monitors helps them track how hard their body is working, preventing PEM. Patients who have learned to listen to their bodies might be able to increase their activity level.

However, ME/CFS is unpredictable. PEM symptoms may not start right after exercise. This makes it important to tailor each treatment plan to the individual, with their input.

Exercise is not a cure for ME/CFS. Vigorous aerobic exercise can benefit people with many chronic illnesses. But people with ME/CFS **do not tolerate** such exercise routines. Standard exercise recommendations for healthy people can be harmful for patients with ME/CFS. However, it is important that patients with ME/CFS undertake activities that they can tolerate, as described above.

Sleep

People with ME/CFS often feel less refreshed and restored after sleep than they did before they became ill. Common sleep complaints include:

- difficulty falling or staying asleep
- extreme sleepiness
- intense and vivid dreaming
- restless legs and nighttime muscle spasms

[Good sleep habits](#) are important for all people, including those with ME/CFS. If people are still not sleeping well after using these tips, they might want to try over-the-counter sleep medicines. If those don't help, their healthcare provider may offer a prescription sleep aid. These medicines should be started at the smallest dose and be used for the shortest time possible.

People might **continue to feel unrefreshed** even after the medications help them get a full night of sleep. If so, they should consider seeing a sleep specialist. Most people with sleep disorders, like sleep apnea (pausing in breathing during sleep) and narcolepsy (excessive daytime sleepiness), respond to therapy. However, for people with ME/CFS, not all symptoms may go away.

Pain

People with ME/CFS often have deep pain in their muscles and joints. They might also have headaches (typically pressure-like) and sore skin when touched.

People with ME/CFS should always talk to their healthcare provider before trying any medication. Doctors may first recommend trying over-the-counter pain relievers, like acetaminophen, aspirin, or ibuprofen. If these do not provide enough pain relief, people with ME/CFS may need to see a pain specialist. People with chronic pain, including those with ME/CFS, can benefit from counseling to learn new ways to deal with pain.

Other pain management methods include stretching and movement therapies, gentle massage, heat, toning exercises, and water therapy. Acupuncture, when done by a licensed practitioner, might help with pain for some patients.

Depression, stress, anxiety

Adjusting to a chronic, debilitating illness sometimes leads to depression, stress, and anxiety. If people with ME/CFS have depression or anxiety, they should be treated.

Some people with ME/CFS might benefit from antidepressants and anti-anxiety medications. However, healthcare providers should use caution in prescribing these medications. Some drugs used to treat depression might worsen other ME/CFS symptoms and cause side effects. When healthcare providers are concerned about patient's psychological condition, they may recommend seeing a mental health professional.

Some people with ME/CFS might benefit from trying deep breathing, muscle relaxation and massage. They also may wish to try movement therapies (such as stretching, yoga, and tai chi). These can reduce stress and anxiety and promote a sense of well-being.

Dizziness and lightheadedness (orthostatic intolerance)

Some people with ME/CFS might also have symptoms of orthostatic intolerance triggered -- or made worse -- when standing or sitting upright. These symptoms can include:

- Frequent dizziness and lightheadedness
- Vision changes (blurred vision, seeing white or black spots)
- Weakness
- Feeling like heart is fluttering or skipping beats
- Feeling like heart is beating too fast or hard

Healthcare providers will often check the person's heart rate and blood pressure to make sure nothing else is wrong. They may recommend the person with ME/CFS see a specialist, like a cardiologist or neurologist.

If symptoms continue but the person doesn't have heart or blood vessel disease, healthcare providers may suggest additional measures. These could include increasing daily fluid and salt intake and using support stockings. If symptoms do not improve, prescription medication can be considered.

Memory and concentration problems

Tools like organizers and calendars can help people manage memory problems. Those with concentration problems may be prescribed stimulant medications, like those typically used to treat Attention-Deficit/Hyperactivity Disorder (ADHD). While stimulants might help improve concentration for some people with ME/CFS, they might lead to the ‘push-and-crash’ cycle and worsen symptoms.

Resources

Could You Have ME/CFS? (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)

ME/CFS is a complex illness and symptoms of ME/CFS may seem similar to many other illnesses. ME/CFS requires **three** symptoms:

1 Not being able to participate in routine activities that were possible before becoming ill, such as work, school, social life, and/or personal life, that:

- Lasts for more than **6 months**
- Is accompanied by **fatigue** that is:
 - Often serious
 - Just started (not lifelong)
 - Not the result of ongoing activities
 - Not from more than usual effort
 - Not made better by rest

2 Post-exertional malaise (PEM). Worsening of symptoms after physical, mental, or emotional effort that would not have caused a problem before the illness. This is sometimes referred to as “crashing” by people with ME/CFS.

3 Unrefreshing sleep. People with ME/CFS may not feel better even after a full night of sleep (e.g., feeling just as tired upon waking up as before going to bed).


In addition, **at least one** of the following symptoms is also required:

Impaired memory or ability to concentrate. People with ME/CFS may have trouble remembering, learning new things, concentrating, or making decisions.

Orthostatic intolerance (symptoms that occur when standing upright). People with ME/CFS may feel lightheaded or dizzy when standing upright and may even faint.

The list of key symptoms is drawn from an Institute of Medicine (IOM) report by an expert committee of the National Academies of Sciences, Engineering, and Medicine and published in 2015: [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#). You may experience some additional symptoms.

Only a healthcare provider can diagnose ME/CFS. A healthcare provider will ask about how often your symptoms occur and how much they affect you. Sometimes you may need to make more than one visit to a healthcare provider before being diagnosed. While not all healthcare providers are familiar with diagnosing ME/CFS, resources are available to help them make a diagnosis.



Centers for Disease Control and Prevention
National Center for Emerging and Zoonotic Infectious Diseases

For more information on ME/CFS, please visit www.cdc.gov/me-cfs.

Patient Toolkit

ME/CFS educational tools to help patients and their families manage their healthcare visits.

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Strategies to Prevent Worsening of Symptoms

These strategies guide healthcare providers in treating their ME/CFS patient's worst symptoms first.

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SOURCES

CONTENT SOURCE:
[National Center for Emerging and Zoonotic Infectious Diseases \(NCEZID\)](#)